



# GA: Recognizing the Burden

Peer Perspective with Dr Nancy Holekamp, Director of Retina Services at the Pepose Vision Institute

*Sponsored by Apellis Pharmaceuticals*

A 2021 survey of those living with geographic atrophy (GA) revealed that this disease has a profound effect on patients' lives, resulting in a large emotional burden and loss of independence. The global Geographic Atrophy Insights Survey (GAINS) (N=203), conducted by The Harris Poll and sponsored by Apellis Pharmaceuticals, found that for nearly 7 in 10 (68%) people living with GA, the impact of vision decline on their independence and quality of life is worse than they expected. There are several reasons for this, which we will explore in the following pages. To alleviate the added burden of misunderstanding or miscommunication, thinking about phrasing key clinical terms in a way that makes them easier for patients to grasp is an important consideration.<sup>1,2</sup>

## Dispel GA Misconceptions

GA is not a well-understood disease. In fact, the GAINS survey found that respondents lacked basic information about GA, which could lead to significant consequences. For example, 76% of patients reported that they attributed their vision loss, prior to their diagnosis, to a natural part of aging. Half of patients (50%) were also under the assumption that wet AMD is the only form of AMD that can lead to vision loss. To that end, patients need a more accurate and comprehensive understanding of GA. Indeed, at diagnosis, patients express a strong desire for

 **86%** wish there were more educational materials available for patients and caregivers

more information to better understand GA. In the current study, 86% of patients wish there were more educational materials for both patients and caregivers. Furthermore, patients want to know how progression can impact their lives. Specifically, 83% said they wish they knew at the time of diagnosis the irreversible impact GA would have on their vision.<sup>1</sup>

 **76%** of people living with GA agree that prior to their diagnosis, they attributed their vision loss to a natural part of aging\*

 **83%** At the time of diagnosis, wish they understood the irreversible impact GA would have on their vision

\*All statistical graphics in this article are from the GAINS study (N=203)

Although we need to communicate the facts about GA, we should also be conscious of how we talk to our patients. One way we simplify communication and reduce misunderstandings at our clinic is to clearly explain what geographic atrophy is at the initial diagnosis. After that, I keep things simple with patients and use the term "GA," rather than "geographic atrophy" or "dry AMD." It may seem like a small thing, but whatever we can do to make the vocabulary easier for patients is worth considering. That said, even simple terms like "blindness" can be misunderstood. When patients hear this word, they think complete darkness, which can make coping with GA much more difficult. Granted, it is challenging to explain the nature of GA vision loss. It's not like wet AMD, where you can show patients a picture simulating the central distortion and blurred area caused by leakage from abnormal blood vessels. GA can produce scotomas, which are experienced as missing vision or lack of resolution. That's very difficult for patients to conceptualize and verbalize, which only adds to our difficulties in communicating about GA and how it affects vision. Also, no two people experience a GA scotoma the same way. Every scotoma is different.<sup>2,3</sup>

As ECPs, we have some misconceptions too. Best corrected visual acuity is widely accepted by the clinical community and regulatory authorities worldwide as a key measure of visual function. However, this is a measure of central acuity of the fovea, and is poorly correlated with GA lesion size. Best-corrected visual acuity does not assess all nuances of comprehensive visual function. GA can grow in a unique, foveal sparing pattern that tends to involve the fovea only late in the course of the disease. Snellen visual acuity measurements do not capture GA. Just because a patient can pick out letters on an eye chart doesn't mean they can read a book or feel comfortable driving. Other measurements are needed. This is also evidenced in The Harris Poll findings. Specifically, nearly 1 in 3 (31%) patients said their vision started to decline or worsen prior to diagnosis with GA. Similarly, it's important to consider all the ways that GA is experienced by patients—beyond visual acuity loss. The survey results elucidate this as well. Specifically, patients most commonly note that they need brighter light when reading or doing close-up work (85%) and that they also experience an inability to drive at night (ie, in the dark) (83%).<sup>1,4</sup>

 **83%** of patients note that they experience **the inability to drive at night**

## Progression of Vision Loss Is Urgent

In contrast to the medical community's perception of GA being a disease that progresses slowly, most patients in GAINS perceive the disease as advancing more quickly than they had originally expected. In fact, most patients surveyed by The Harris Poll were surprised by the severity and speed of the disease's impact on their vision. Specifically, 77% said that the impact on their vision happened faster than they expected and 68% said the impact of the vision decline on their quality of life and independence is worse than they expected.<sup>1</sup>



agree the **impact** of vision decline on **QOL** and **independence** is **worse than they expected**

As clinicians, we talk about GA being a slow-moving disease because we are comparing it to the faster progression of vision loss with untreated wet AMD, but patients may not be able to relate to this. We need to rethink how we describe disease progression. From the patient's perspective, vision loss may occur surprisingly fast because it's closely tied to their experience of the world and their quality of life. With that in mind, when discussing GA with patients, it's much clearer to explain what it will be like to experience the loss. Consider that the GAINS survey found 70% of patients rely on a caregiver to help with various tasks—most commonly driving at night (42%) or during the day (33%).<sup>1</sup> Any loss of independence is likely to substantially impact their quality of life.



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**"In contrast to the medical community's perception of GA being a disease that progresses slowly, most patients in GAINS perceive the disease as advancing more quickly than they had originally expected."**

**~8** out of **10** (77%) agree their vision was impacted **faster than they expected**

## Acknowledge Loss of Independence

Many of our GA patients' needs are met by spouses, sons, daughters and other caregivers. This might include driving them to medical appointments, shopping and preparing meals, reading mail, paying bills, and more. Adult children wonder when they should "take away" the car keys, write all of the checks, put out medications, and manage all the little things that we often take for granted but are indicators of our independence. Caregivers may perceive all of this responsibility as a burden, but in my experience, it's also often uncomfortable for the GA patients who don't want to rely on others, particularly their children.<sup>1</sup>

In patients who have GA, loss of independence may not be something that families grapple with decades after a diagnosis. It can happen much more quickly. On average, surveyed patients started relying on caregiver support as early as 2.6 years following diagnosis. In the US, caregiver dependency begins just 1.6 years on average after diagnosis. But asking for this help isn't easy. Although two-thirds (68%) of patients feel dependent on others due to their vision loss, more than half (53%) feel uncomfortable asking for help.<sup>1</sup>

 **1.6** YEARS In the US, **caregiver dependency begins just 1.6 years after diagnosis on average**

Of course, not everybody has a strong support network. Some patients have no one to turn to for the level of care they need with GA. We see this all the time in our clinic. As the patient's vision gets worse, they take a bus or a taxi to their appointment. In my clinic, we sometimes see patients who are struggling with personal grooming—through no fault of their own. It's important to look out for these subtle cues. When you talk to these patients, they might share that they're also having difficulty keeping their houses clean. In many cases, these patients may have to move into assisted living, which can be very difficult for those who cherish their independence or have lived in their family home for a long time.<sup>1</sup>

**"It may seem like a small thing, but whatever we can do to make the vocabulary easier for patients is worth considering."**

## Recognize Emotional Toll

Most patients surveyed by The Harris Poll (68%) find it hard to enjoy life as much as they had prior to their GA diagnosis. For example, many report that the disease has a major or moderate negative impact on their ability to pursue activities such as driving (74%), reading (68%), traveling (62%), hobbies and social activities (43%), and the ability to work or volunteer (42%). Consequently, patients most commonly report feeling anxious (46%), powerless (39%), or frustrated (33%) as a result of their vision loss or impairment. Indeed, GA can have a deep emotional toll, so much so that about 1 in 3 (35%) patients reported that they had withdrawn from their social lives due to their condition.<sup>1</sup>

 **~1 in 3 (35%)** withdrew from their **social lives** due to their condition

The atmosphere in the exam room often reflects this. When you're with a GA patient, the office visits tend to be very muted and the tone of the office visit is one of empathy and sympathy. Sometimes, patients are depressed and therefore quiet, and you have to rely on what the caregiver is noticing. It's a drain on everyone—medical staff included. As doctors, we know it's our job to help, yet our options are currently very limited. Meanwhile, it's a race against the clock as patients continue to progressively and irreversibly lose vision.<sup>1,5</sup>

 **68%** of patients **find it hard to enjoy life as much as they had prior to their GA diagnosis**

**“As clinicians, we talk about GA being a slow-moving disease because we are comparing it to the faster progression of vision loss with untreated wet AMD, but patients may not be able to relate to this.”**

## Keeping a Positive Attitude

Mustering optimism can be a challenge in these circumstances, but I try to be forward thinking because I know that we must do everything we can to help these patients. This begins with awareness. We need to educate our patients about the realities of GA. GAINS found that 91% want more information and options about GA to feel empowered to take control of their disease.<sup>1</sup>



**91%** want more information and options about GA to feel empowered to take control of their disease

We can also do more to bring attention to GA within our profession. My hope is that one day we will be with GA where we are with wet AMD. In the meantime, it's important to recognize that there are really big differences in patient experiences with these 2 conditions and in how we need to approach care and communication. As with any disease, the earlier we detect it, the better. This will require further education of all primary eye care providers and increased utilization of non-invasive imaging techniques such as fundus autofluorescence and spectral domain OCT. We need to advocate for our patients by educating our peers about the importance of early detection and early action.<sup>6,7</sup>



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## Survey Design

The global Geographic Atrophy Insights Survey (GAINS) was sponsored by Apellis and conducted by The Harris Poll between October 12 to December 10, 2021. To accommodate visually impaired respondents, the survey was conducted online and via the telephone among 203 participants aged 60 or over (mean age 70 years) residing in the US, UK, France, Germany, Italy, the Netherlands, Sweden, Canada, and Australia who self-reported that they have been diagnosed with age-related macular degeneration (AMD) and have dry AMD in at least 1 of their eyes. They must also have indicated that they have advanced atrophic age-related macular degeneration or advanced atrophic AMD, advanced/late/late-stage dry age-related macular degeneration or advanced dry AMD, or geographic atrophy (GA) in 1 or both of their eyes. Included patients must have been currently experiencing at least 3 GA symptoms and currently do/used to do/or have been suggested by an eye care professional but have not done at least one of the following: Take a high-dose formulation of antioxidant vitamins and minerals, stop smoking, maintain a healthy weight and exercise regularly, choose a healthy diet, manage other medical conditions, have check-ups of the retina regularly, or wear sunglasses with UV protection. Included patients must not have been diagnosed with glaucoma, Stargardt disease, or dementia, or be receiving regular injections into the affected eye every 4 to 6 weeks.

Raw data were not weighted at the individual country level and are therefore only representative of the individuals who completed the survey. For the global total, a post-weight was applied to adjust for the relative size of each country's adult population within the total adult population across all countries surveyed.

Respondents for this survey were selected from among those who have agreed to participate in our surveys. The sampling precision of Harris online polls is measured by using a Bayesian credible interval. For this study, the sample data is accurate to within  $\pm 7.8$  percentage points using a 95% confidence level and  $\pm 6.5$  percentage points using a 90% confidence level. This credible interval will be wider among subsets of the surveyed population of interest.

All sample surveys and polls, whether or not they use probability sampling, are subject to other multiple sources of error which are most often not possible to quantify or estimate, including, but not limited to coverage error, error associated with nonresponse, error associated with question wording and response options, and post-survey weighting and adjustments.